D5.9 Patient & Citizens FORUM

FINAL REPORT

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QUANTUM summary	The QUANTUM project aims to develop and implement a labelling mechanism to support the assessment of health data quality, utility and maturity, with the objective of enabling its future adoption within the HealthData@EU framework. To achieve this, QUANTUM is structured into five technical Work Packages (WPs), each addressing a specific component of the overall approach. WP1 focuses on the conceptualization and technical specification of the data quality, utility and maturity label. WP2 is dedicated to the design and small-scale testing of the labelling mechanism. WP3 supports the implementation of the label across selected data holders. WP4 engages the community of data quality users, including researchers and other stakeholders. WP5 focuses on outreach activities, addressing a broader range of stakeholders and initiatives connected to the development of HealthData@EU.
Deliverable Abstract	This deliverable reports on the objectives, implementation and results of the QUANTUM Patients and Citizens Forum. The Patients and Citizens Forum served as a dedicated engagement platform within the project, focusing on the perspectives of patients and citizens in relation to health data and its secondary use. A series of interactive online sessions were organised to introduce key concepts, explore levels of understanding, and gather feedback from participants. The sessions combined presentations, open discussions and interactive exchange formats to capture both structured input and experiential perspectives. In parallel to these structured activities, insights were collected through continuous engagement and listening activities conducted throughout the project. These included participation in conferences, workshops and public events, as well as contributions to international discussion formats such as the Patient Engagement Open Forum (2023, 2024 and 2025), enabling exchange with an international community of approximately 150 patient experts. In addition, social media listening activities were carried out to observe how QUANTUM and the concept of health data quality labelling are perceived and discussed across relevant audiences. The combination of structured sessions and continuous listening activities provided a broader evidence base for understanding patient and citizen perspectives. The content and outcomes of the forum sessions are

	presented in this deliverable, together with an analysis of the insights collected and their relevance for the QUANTUM project. Across the sessions and engagement activities, participants consistently highlighted the need for clear and accessible communication, improved contextualization of health data concepts, and greater transparency regarding the use of health data. Observations indicate that awareness of secondary use of health data remains limited, while interest and willingness to engage increase when information is presented in a clear and relatable manner. These findings underline the importance of aligning communication and engagement approaches with the needs and expectations of patients and citizens, as a key factor for supporting trust, understanding and the uptake of health data initiatives within the European Health Data Space (EHDS).
Keywords	Patient / Citizen Forum Patient Involvement, Patient / Citizen Engagement Digital – Data – Health Literacy Data quality and utility label European Health Data Space (EHDS)

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QUANTUM CONSORTIUM			
#	Short Name	Organisation Name	Country
1	IACS	INSTITUTO ARAGONES DE CIENCIAS DE LA SALUD	ES
2	Sciensano	SCIENSANO	BE
3	Health Data Hub	PLATEFORME DES DONNEES DE SANTE	FR
3.1	HOSPICES LYON	HOSPICES CIVILS DE LYON	FR
3.2	HOSP TOULOUSE	CENTRE HOSPITALIER UNIVERSITAIRE DE TOULOUSE	FR
3.3	CHU Bordeaux	CHU HOPITAUX DE BORDEAUX	FR
4	I-HD	THE EUROPEAN INSTITUTE FOR INNOVATION THROUGH HEALTH DATA	BE
5	UCSC	UNIVERSITA CATTOLICA DEL SACRO CUORE	IT
6	BBMRI-ERIC	BIOBANKS AND BIOMOLECULAR RESOURCES RESEARCH INFRASTRUCTURE CONSORTIUM	AT
7	DIGITALEUROPE	DIGITALEUROPE AISBL	BE
8	GÖG	GESUNDHEIT OSTERREICH GMBH	AT
9	UPV	UNIVERSITAT POLITECNICA DE VALENCIA	ES
10	HEALTH-RI	STICHTING HEALTH-RI	NL
11	EUHA	EUROPEAN UNIVERSITY HOSPITAL ALLIANCE	BE
12	AP-HP	ASSISTANCE PUBLIQUE HOPITAUX DE PARIS	FR
13	VIB	VIB VZW	BE
14	CIPH	HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO	HR
15	HUS	HUS-YHTYMA	FI
16	THL	TERVEYDEN JA HYVINVOINNIN LAITOS	FI
17	ECRIN	ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK	FR
18	BFARM	BUNDESINSTITUT FUR ARZNEIMITTEL UND MEDIZINPRODUKTE	DE
19	HIQA	HEALTH INFORMATION AND QUALITY AUTHORITY	IE
20	ISS	ISTITUTO SUPERIORE DI SANITA	IT
21	CESSDA ERIC	CESSDA ERIC	NO
21.1	KNAW	KONINKLIJKE NEDERLANDSE AKADEMIE VAN WETENSCHAPPEN - KNAW	NL
21.2	EKKE	ETHNIKO KENTRO KOINONIKON EREVNON	EL
22	e-helse	DIREKTORAT FOR E-HELSE	NO
23	U.PORTO	UNIVERSIDADE DO PORTO	PT
24	SPMS	SERVICOS PARTILHADOS DO MINISTERIO DA SAUDE EPE	PT
25	NIJZ	NACIONALNI INSTITUT ZA JAVNO ZDRAVJE	SI
26	ERASMUS MC	ERASMUS UNIVERSITAIR MEDISCH CENTRUM ROTTERDAM	NL
27	edha	EUROPEAN DIGITAL HEALTH ACADEMY GGMBH	DE
28	HDR UK	HEALTH DATA RESEARCH UK	UK
29	UESSEX	UNIVERSITY OF ESSEX	UK
30	INSERM	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE	FR

The European Commission's evaluation determines the final approval of QUANTUM Deliverables.

QUANTUM
THE HEALTH DATA QUALITY LABEL

Developing a data quality and utility label for the European Health Data Space.

Project number: 101137057
Call: HORIZON-HLTH-2023-TOOL-05
Topic: HORIZON-HLTH-2023-TOOL-05-09
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Duration: 30 months

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List of Abbreviations and Acronyms	
DCAT	Data Catalog Vocabulary
DQV	Data Quality Vocabulary
EDICs	European Digital Infrastructure Consortia
EHDS	European Health Data Space
F4P	Fit-for-purpose
HDAB	Health Data Access Body
HealthDCAT-AP	The HealthDCAT Application Profile
PROV-O	The PROV Ontology
RDF	Resource Description Framework
	Additional Terms relevant for patient and citizen engagement
RWE	Real-World Evidence (data from real-life healthcare settings)
WP	Work Package (project component)
	Secondary use of health data – use of health data for research, innovation and policy purposes

Introduction

The deliverable reports on the design, implementation and results of the QUANTUM Patients and Citizens Forum, including the development of a patient and citizen community within the project.

The forum was established as a structured engagement model to integrate patient and citizen perspectives into the development of the QUANTUM data quality and utility label under the European Health Data Space (EHDS).
In addition, the Forum aimed to provide accessible information about the QUANTUM project, its objectives and activities, and to support understanding of health data and its secondary use among patients, patient organisations and citizens.

Over the course of the project, a series of five online sessions was conducted between March 2025 and May 2026. The sessions addressed key topics related to the QUANTUM project, as well as broader aspects of health data and the secondary use of health data, with a focus on understanding, relevance and practical implications for patients and citizens.
In contrast to technically oriented stakeholder activities within the project, the Patients and Citizens Forum focused on how non-expert audiences interpret and assess health data-related concepts, including transparency, relevance and trust.

Situated within QUANTUM's broader objective to support the implementation of a data quality and utility label for HealthData@EU, the infrastructure designed to enable the secondary use of health data across Europe, the Patients and Citizens Forum was not conceived as a dissemination activity, but as an exploratory and iterative engagement space. It enabled the collection of qualitative insights to better understand how health data concepts are perceived outside expert communities and how communication and engagement approaches can be improved.

Each session combined introductory presentations with interactive discussion formats, allowing participants to share perspectives, raise questions and reflect on the relevance of the topics discussed. In addition, participants were provided with opportunities to access project-related resources and to raise questions beyond the sessions, including through dedicated communication channels. Insights were collected through continuous engagement and listening activities conducted throughout the project, including participation in conferences, workshops and international discussion formats, as well as targeted research and social media listening activities to observe how QUANTUM and the concept of health data quality labelling are perceived across different audiences.
This deliverable documents the objectives, implementation and outcomes of the Patients and Citizens Forum and analyses how the insights collected contribute to a better understanding of communication needs, expectations and potential barriers related to the secondary use of health data. It highlights the importance of contextualisation, accessibility and trust as key factors influencing engagement, and provides input for the broader positioning and uptake of health data initiatives within the EHDS and HealthData@EU framework.

Background and scope

2.1 Purpose and objectives of the Patients and Citizens Forum

The purpose of the QUANTUM Patients and Citizens Forum was to serve as a dedicated engagement and information platform within the project, focusing on the perspectives of patients and citizens in relation to health data and its secondary use.

While the broader QUANTUM Project Forum primarily addressed technical stakeholders and project deliverables, the Patients and Citizens Forum complemented this approach by exploring how non-expert audiences understand, interpret and assess health data-related concepts, in particular the secondary use of health data, as well as its implications and related developments.

The forum was designed not only to provide accessible information about the QUANTUM project and its objectives, but also to collect qualitative insights regarding expectations, perceptions and levels of understanding among patients and citizens.

Engagement was organised through a series of online sessions, complemented by continuous listening and interaction activities, allowing for both structured input and ongoing exchange throughout the project.

The objectives of the Patients and Citizens Forum were to:

- assess awareness and understanding of health data and its secondary use among patients and citizens
- explore expectations regarding transparency, trust and communication
- identify barriers to understanding and engagement
- provide input to support the communication, usability and broader acceptance of the QUANTUM data quality and utility label
- contribute to the alignment of engagement approaches with the needs of patient and citizen communities

2.2 Methods

The Patients and Citizens Forum acted as a dedicated engagement and information platform, aiming to connect patients, citizens and patient experts with the QUANTUM project and its developments, in particular in relation to the secondary use of health data. While the activities were aligned with the European context of the QUANTUM project and the implementation of the EHDS, the engagement approach also reflected broader international perspectives and contributed to discussions beyond the immediate project environment.

At its core were interactive online sessions, complemented by continuous communication and engagement activities throughout the project. Over the course of the project, a series of five online sessions was conducted between March 2025 and May 2026, addressing key topics related to the QUANTUM project, as well as broader aspects of health data and the secondary use of health data.
Forum sessions were organised using Webex and managed at project level. The sessions were recorded and made available via the project website to enable participants and interested audiences to revisit the content and ensure broader accessibility.

Interactive formats were applied during and after the sessions to gather feedback and insights from participants, including open discussions and structured input formats. In addition to the sessions, participants were provided with access to project-related materials and opportunities for follow-up exchange through dedicated communication channels. This enabled participants to engage with the content beyond the sessions and to contribute questions and reflections over time.

Furthermore, continuous engagement and listening activities were conducted throughout the project. These included participation in conferences, workshops and international discussion formats, as well as targeted research and social media listening activities.
These activities were complemented by project-related communication efforts and additional outreach activities conducted through established patient and citizen networks. In particular, initiatives led by Data Saves Lives Germany (DSL DE) and the european digital health academy (edha) contributed to increasing the visibility and accessibility of the topic within patient communities.
As part of these efforts, relevant concepts such as the secondary use of health data, health data labelling and health data quality were communicated in a structured and accessible manner, including through dedicated educational formats such as the “DSL DE Fachgedöns 2025/26” series, developed and implemented by Data Saves Lives Germany (DSL DE), which provided accessible explanations of key concepts and included references and links to the QUANTUM project. The resource was made available as an openly accessible format in German and English (see: https://www.datasaveslives.de/glossary), supporting broader awareness and contributing to sustained engagement with QUANTUM-related topics beyond the immediate project context.

In addition, opportunities for further collaboration and engagement were offered to support the integration of QUANTUM into established patient and citizen activities. These included invitations to participate in dedicated sessions, opportunities to contribute to blog-based communication formats, and options for extended visibility within existing community structures.
While these opportunities were made available, their uptake remained limited. The provision of these formats nevertheless reflects the broader engagement approach applied, aiming to create multiple entry points for participation, visibility and knowledge exchange.

The identification and selection of these engagement opportunities, as well as the underlying analysis, were documented and shared within the project, providing a transparent basis for the approach taken. The combination of structured sessions and continuous listening activities provided a comprehensive basis for capturing patient and citizen perspectives.
This approach not only supported the objectives of the QUANTUM project within the European context, but also demonstrated how patient and citizen engagement can be structured in a way that is transferable and relevant beyond the immediate project environment. The activities therefore contributed to broader discussions on how to effectively engage patient and citizen communities in the context of the secondary use of health data.

2.2.1 Patient and Citizens Forum session structure

Each Patients and Citizens Forum session combined presentations with interactive discussion formats. Depending on the topic, sessions varied between more workshop-oriented formats with active feedback collection and sessions focused on presentations and open exchange.

Where appropriate, structured approaches were used to gather input from participants during or after the sessions, including interactive tools and follow-up formats.

Key elements of the sessions included:

1. **Presentation of QUANTUM-related topics:** Introduction of relevant concepts, of Health Data, the EHDS, aspects of the QUANTUM work, with a focus on the secondary use of health data.
2. **Interactive discussions:** Open or guided discussions allowing participants to share perspectives, ask questions and reflect on the topics presented.
3. **Feedback collection:** Structured and unstructured input gathered during and after sessions to capture participant perspectives and insights.

Structured feedback tools were applied where appropriate; however, the level of engagement varied depending on the format, the theme and complexity of the topics discussed. In particular, it was observed that participants were often more inclined to engage through open discussion formats rather than structured feedback tools.
This highlights the importance of aligning engagement approaches with the needs and preferences of patients and citizens. While structured tools can support the collection of measurable input, open formats proved particularly valuable in enabling trust, dialogue and meaningful exchange, especially in the context of complex topics such as the secondary use of health data.

2.2.2 Collecting feedback outside in the Patient and Citizens Communities

In addition to the structured online sessions, feedback and insights were collected through continuous engagement and listening activities conducted throughout the project.
Rather than relying on formalized feedback mechanisms, the approach focused on capturing qualitative insights through ongoing interactions with patients, citizens and patient experts across different settings.
These activities were primarily carried out through initiatives led by the european digital health academy (edha), in close connection with Data Saves Lives Germany (DSL DE), and included participation in conferences, workshops and international discussion formats, as well as targeted research and social media listening activities. This enabled the observation of how QUANTUM and the concept of health data quality labelling are perceived and discussed, particularly in relation to the secondary use of health data.
The approach allowed for the identification of recurring themes, expectations and challenges, complementing the insights gathered during the forum sessions.

2.3 Patients- and Citizen Forum members

Participation in the Patients and Citizens Forum was open and inclusive, allowing patients, citizens, patient experts and interested stakeholders to join the sessions based on interest and relevance of the topics discussed.
Rather than relying on a fixed or formally defined membership structure, the forum followed a flexible participation approach. Invitations were extended through existing networks, project-related communication channels outside of quantum and relevant stakeholder connections, enabling a diverse group of participants to engage with the topics. This approach was intentionally designed to support voluntary and self-determined participation, recognizing that engagement in patient and citizen communities is often influenced by individual interest, confidence and relevance of the topic. Providing open access without continuous prompting or pressure allowed participants to join at their own pace and contributed to creating a more inclusive and accessible environment.

While certain organisations and stakeholder groups were identified as relevant for participation, engagement remained voluntary and dynamic, reflecting the nature of patient and citizen involvement in the context of complex topics such as the secondary use of health data.

As a result, participation varied across sessions, and a fully consolidated and static list of members was not maintained. Instead, the forum brought together a changing group of participants, contributing different perspectives depending on the topic and context.

A list of invited organisations and stakeholders may exist at project level; however, such lists should be understood as indicative of outreach efforts rather than a definitive representation of active participation.

Session-specific attendance lists were maintained for organisational purposes, but given the open and topic-driven nature of participation, they do not constitute a stable or representative participant cohort.

Examples of participating organisations include, among others, the GKV-Spitzenverband (Germany), IPPOSI – the Irish Platform for Patient Organisations, Science and Industry (Ireland), and EFPIA – the European Federation of Pharmaceutical Industries and Associations (Belgium), illustrating the diversity of stakeholders engaged across sessions. These examples are indicative and do not represent a complete or systematic listing of participants.

Due to the open and voluntary nature of participation, and the absence of a structured consent process for public attribution, individual participants are not listed.

While quantitative indicators such as participation numbers or engagement metrics provide a useful reference point, they do not fully capture the extent of interest and interaction within patient and citizen communities.
Observations from digital engagement and communication activities suggest that a significant share of interaction occurs beyond visible metrics, including individuals who repeatedly access content without actively engaging through measurable actions such as following or providing feedback.

This highlights the importance of considering both visible and non-visible forms of engagement when assessing reach and impact, particularly in the context of sensitive and complex topics such as the secondary use of health data.
Such patterns of engagement can contribute to more sustained and long-term interaction, supporting the development of trust and strengthening the relationship between patients, citizens and the topic. This is particularly relevant for the continued development, acceptance and implementation of data-related tools and approaches within patient-relevant systems, where trust and sustained interest are key factors for meaningful uptake.

3 Patient and Citizens Forum implementation and results

3.1 Overview of the Sessions

An overview of the Patients and Citizens Forum Sessions is presented in Table 1. All Sessions were documented through presentation materials and recordings, which are available as openly accessible resources at the QUANTUM You Tube Channel: https://www.youtube.com/@QUANTUMprojetctEU

Table 1: Overview of the Patient and Citizen Online Sessions

	1. Online Session	2. Online Session	3. Online Session	4. Online Session	5. Online Session
Date and time	25th March 2025	6th May 2025	25th June 2025	8th October 2025	14th April 2026
Main theme	What kind of Health Data do we have – Understanding Health Data Types and their Impact	Why should I care? – The Benefits of Health Data Labeling for Patients & Citizens	Trust, Privacy & EHDS – The Ethical and Legal Side of Health Data	The European Health Data Space – Progress, News and what's next for Patients	QUANTUM – Meet the Faces behind the Project
Feedback channel	Presentation, Discussion, Mentimeter	Presentation, Discussion, Mentimeter	Presentation, Discussion, Mentimeter	Presentation, Discussion, Mentimeter	Presentation, Discussion, Mentimeter
Organisation responsible organizing	edha (content, speakers, programme) Digital Europe (technical setup and recordings)	edha (content, speakers, programme) Digital Europe (technical setup and recordings)	edha (content, speakers, programme) Digital Europe (technical setup and recordings)	edha (content, speakers, programme) Digital Europe (technical setup and recordings)	edha (content, speakers, programme) Digital Europe (technical setup and recordings)
Number of participants	Approx. 118	52	44	38	64

3.2 Patients and Citizens Forum contents and results

3.2.1 Session 1 – What kind of data do we have

The first Patients and Citizens Forum session, held on 25 March 2025, focused on introducing the concept of health data and building a shared understanding of its different types and uses as a foundation for further discussions throughout the forum series.

The session was led by Birgit Bauer (european digital health academy, edha), and complemented by expert contributions from Prof. Fidelia Cascini and Beatriz Barros. While the session was intentionally designed from a patient and citizen perspective, the contributions of the invited experts provided important links to the broader European policy and research landscape, including developments around the European Health Data Space (EHDS) and the secondary use of health data.

A key objective of the session was to make abstract and often technical concepts around health data more tangible. This included explaining different types of health data, how they are generated, and how they are used across healthcare systems and research environments. Particular attention was given to translating terminology into accessible and relatable language, enabling participants to connect the topic to their own experiences.

During the discussion, participants engaged actively and raised fundamental questions that reflected both curiosity and uncertainty. One recurring theme was the lack of awareness regarding the breadth of health data collection and use. As one participant put it:

"What kind of data is actually collected about me without me really noticing it?"

This question illustrates a central challenge: while health data plays an increasingly important role in healthcare and research, its scope and implications are often not clearly understood by patients and citizens. The discussion further revealed that participants were particularly interested in understanding how their data is used beyond direct care, especially in the context of research and system-level decision-making.
The session demonstrated that establishing a basic, shared understanding is a critical prerequisite for meaningful engagement. Without this foundation, more advanced discussions—such as data quality, labelling or governance—remain difficult to access.
At the same time, the session demonstrated that participants are willing to engage with complex topics when they are presented in a clear and relevant way. The combination of patient-centred explanation and expert input proved effective in bridging the gap between technical concepts and real-world understanding.

Overall, the session provided important insights into the knowledge gaps, expectations and concerns of patients and citizens, and set the tone for subsequent sessions by emphasizing the importance of clarity, context and trust in discussions around the secondary use of health data.
In addition, the session highlighted practical considerations for the format itself. It became evident that the one-hour timeframe, while appropriate for accessibility, can be limiting when addressing complex and multi-layered topics. As a result, subsequent sessions maintained the overall format but were structured more deliberately to balance information input, discussion and reflection.
The session also underlined the importance of using clear and accessible language. It was observed that highly technical terminology can create barriers to engagement, particularly for participants without a professional or academic background in health or data. As a result, expectations for subsequent speakers were adjusted to ensure that content is communicated in a way that remains understandable and relevant for patients and citizens, while still addressing the complexity of the topic.
This reflects an adaptive approach, taking into account both the complexity of the subject and the needs of participants.

3.2.2 Session 2 – Why should I care? The Benefits of Health Data Labelling for Patients and Citizens

The second Patients and Citizens Forum session, held on 6 May 2025, focused on the relevance of health data and, in particular, on the question of why patients and citizens should care about topics such as data quality and health data labelling.
In this session, the format was slightly adapted, with Adam Skali (Institute of Human Centered Health Innovation, IHCHI, Poland) taking on the role of moderator, allowing Birgit Bauer (Germany, european digital health academy, edha) to contribute as a speaker.
The session brought together a diverse group of speakers, including Patient Advocate Sheila Khawaja (Italy), Dr. Katharina Schüller (Germany), Lars Münter (Denmark/Sweden) and PD Dr. Benjamin Friedrich (Germany), combining perspectives from patient advocacy, data science, healthcare and digital health innovation.

A particularly important aspect of this session was the inclusion of two patient advocates as speakers. Both Sheila Khawaja (Italy), living with a rare disease, and Birgit Bauer (Germany), living with multiple sclerosis, contributed their perspectives, grounding the discussion in real-life experience and highlighting the relevance of the topic from a patient point of view.

The session focused on making the concept of health data labelling tangible and relevant. Discussions explored how data quality, transparency and context influence trust, and how improved data use can contribute to better healthcare outcomes and system-level decision-making.
During the discussion, it became clear that relevance is a decisive factor for engagement. Participants showed interest when connections to real-life implications were made, but also raised critical questions around personal benefit and impact. A recurring underlying question was:

"What does this actually change for me?"

This reflects a central insight: abstract concepts such as data quality or labelling only become meaningful when they are linked to tangible outcomes for individuals. Without this connection, engagement remains limited.
In addition, it became evident that for many participants, the topic itself had not previously been a subject of active consideration. Insights gathered through accompanying outreach activities, including communication efforts via Data Saves Lives Germany (DSL DE), showed that patients tend to focus primarily on the use of health data in direct care settings, where the relevance for diagnosis and treatment decisions is immediate and clear.

By contrast, the secondary use of health data—such as for research or public health purposes—was often perceived as distant or abstract. Among citizens in particular, a recurring perspective was that health data is only relevant in the context of illness, leading to limited perceived personal relevance.
This highlights a key challenge: the need to clearly communicate that the use of health data, including its secondary use, has broader implications that can affect both patients and citizens, for example in the context of public health, research and healthcare system improvements.

The session further highlighted that trust plays a key role in how patients and citizens perceive the use of health data. While participants acknowledged potential benefits, they also emphasized the need for transparency, understandable communication and clear value.
Overall, the session marked an important shift from basic understanding towards relevance and impact. It reinforced the importance of connecting technical developments to real-world meaning and demonstrated that patient-centred perspectives are essential for building trust and sustaining engagement.

3.2.3 Session 3 – Trust, Privacy & EHDS: The Ethical and Legal Side of Health data

The third Patients and Citizens Forum session, held on 25 June 2025, focused on trust, privacy and the ethical and legal dimensions of health data, with particular attention to the European Health Data Space (EHDS).
The session was moderated by Birgit Bauer (Germany, Digital Health and Data Expert, Patient Expert, Coordinator Data Saves Lives Germany), ensuring a structured and accessible discussion environment.

The session brought together a diverse group of speakers, including Prof. Ricard Martinez (Spain, Universitat de València), Prof. Dr. Irit Nachtigall (Germany, Charité Berlin) and Patient Advocate Pieter van Galen (Belgium), combining perspectives from legal, clinical and patient domains.

The discussion focused on how trust is built—or undermined—when it comes to the use of health data, particularly in the context of its secondary use. Regulatory frameworks such as the EHDS and GDPR were discussed as important structural elements designed to ensure data protection, governance and accountability.

A central dynamic of the session was the tension between regulatory frameworks and individual perception. While legal and technical safeguards are designed to enable secure and responsible data use, participants highlighted that trust is not automatically created through these mechanisms.

Questions raised during the session reflected this gap between system design and individual understanding, for example:

“How can I be sure that my data is really used in a way that benefits me or others?”

This illustrates a key insight: trust is not purely a legal or technical concept, but a relational one. It is shaped by transparency, communication and the ability of individuals to understand and contextualize how their data is used.

The discussion further highlighted that concerns around privacy are often closely linked to a lack of visibility and understanding. While many participants are aware of the existence of frameworks such as the GDPR, there is often limited understanding of what these regulations actually mean in practice.

This can be attributed in part to the complexity and inaccessibility of legal texts, which are often perceived as difficult to understand and not directly relevant to everyday life. As a result, awareness of regulation does not necessarily translate into confidence or trust.

This reveals a critical gap: knowing that regulatory frameworks exist is not sufficient to build trust. When individuals do not fully understand how their data is protected or used, uncertainty remains—and this is where trust can be lost, despite the presence of robust legal structures.

Participants therefore emphasized the need for clearer, more accessible communication and more transparent information about how health data is handled in practice. Strengthening understanding through communication was seen as a key factor in building trust and enabling more informed engagement with the topic.

In addition, it was observed that while the sessions were generally well received, the topics discussed were often perceived as complex and challenging. This highlights the need to complement live sessions with additional communication channels and accessible resources.

Providing opportunities for participants to revisit content at their own pace—such as through recordings or supporting materials—was identified as an essential element in enabling understanding and sustained engagement. Not all patients and citizens are equally able to process complex information in real time, due to differences in health literacy, cognitive capacity and individual circumstances.

This is particularly relevant for groups such as older adults or individuals living with chronic conditions, where cognitive load and processing capacity can vary. Offering flexible access to information allows individuals to engage with the topic in their own time and according to their needs.

Such approaches were found to support not only understanding but also longer-term engagement, helping individuals to gradually build confidence and become part of the broader community around the topic.

Overall, the session demonstrated that trust is a key enabler for engagement and acceptance. It also showed that building trust requires more than regulation—it requires continuous communication, transparency and the inclusion of patient and citizen perspectives.

One of the most important key learnings: Trust cannot be established through regulation alone. While frameworks such as the EHDS and GDPR provide an essential foundation, meaningful trust is built through transparency, understandable communication and the ability of patients and citizens to relate data use to real-world benefits and safeguards.

3.2.4 Session 4 – The European Health Data Space: Progress, News and What's Next for Patients

The fourth Patients and Citizens Forum session, held on 8 October 2025, focused on the European Health Data Space (EHDS), its current developments and its relevance for patients and citizens.

The session was moderated by Birgit Bauer (Germany, Digital Health and Data Expert, Patient Expert, Coordinator Data Saves Lives Germany), ensuring continuity within the forum series.

The session brought together a diverse group of speakers, including Dr. Katharina Schneider (Germany, Head of the Data Access and Coordination Office, Federal Institute for Drugs and Medical Devices – BfArM), Antonella Cardone (Belgium, Cancer Patients Europe, Brussels) and Carola Schulz (Germany, empirica Gesellschaft für Kommunikations- und Technologieforschung GmbH).

The session aimed to provide participants with an overview of current developments related to the EHDS and to translate these into a patient- and citizen-relevant context.

While interest in the topic was clearly present, the discussion showed that for many participants, the EHDS remains abstract and difficult to grasp. Participants expressed a willingness to understand the topic, but also highlighted the challenge of navigating fragmented and often highly technical information.

One participant summarized this challenge clearly:

"There is so much information, but I don't really know what it means for me."

This reflects a central observation from the session: the challenge is not the lack of information, but the lack of orientation. Without clear structure and contextualization, even relevant information can become overwhelming and difficult to process.

Participants indicated that more structured, accessible and clearly framed communication would support understanding and engagement. In particular, there was a need to better connect policy developments with real-life implications for patients and citizens.

Another recurring theme was the call for greater transparency. Many aspects of health data governance and policy development were perceived as complex and not easily accessible, which can lead to uncertainty, skepticism and, in some cases, mistrust.

In addition, perspectives from patient advocacy communities highlighted a broader concern: decisions related to health data and regulation are often perceived as being made without sufficient opportunity for patients and citizens to contribute or be heard.

This sentiment was reflected in statements such as:

"Decisions are made over my head."

Such perceptions underline the importance of not only communicating decisions more clearly, but also ensuring that opportunities for participation are visible, accessible and meaningful. Transparency and involvement are closely linked, and both are essential for building trust and long-term engagement.

For projects such as QUANTUM, this highlights the importance of actively integrating patient and citizen perspectives—also when these perspectives may challenge existing approaches.

Ensuring that patient voices are not only included but genuinely heard, and that they are involved early in decision-making processes, can significantly strengthen both the relevance and acceptance of project outcomes.

Involving patients and citizens in a meaningful way can also create additional value beyond the project itself. When participants feel included and taken seriously, they are more likely to become active communicators and ambassadors. This, in turn, can support broader reach, increased visibility and stronger engagement with the project and its objectives.

3.2.5 Session 5 – QUANTUM: Meet the Faces behind the Project

The fifth Patients and Citizens Forum session, held on 14 April 2026, took a different approach compared to the previous sessions. Rather than focusing on a specific thematic aspect of health data, the session aimed to introduce the people behind the QUANTUM project and provide a more personal perspective on the work carried out.
The session was moderated by Birgit Bauer (Germany, Digital Health and Data Expert, Patient Expert, Coordinator Data Saves Lives Germany) and brought together representatives from different parts of the QUANTUM consortium.
The speakers included Francisco Estupiñán-Romero (Data Scientist for the Health Services and Policy Research Group, Institute for Health Sciences in Aragón – IACS, Work Packages 1 & 2), Carlos Telleria Orriols (Instituto Aragonés de Ciencias de la Salud – IACS, Work Package 3) and Maïté Vandevyvere (eLearning Implementor, The European Institute for Innovation through Health Data, Work Package 4).

The objective of the session was to create a more direct and relatable connection between the project and its audience. By giving visibility to the individuals involved, the session provided insights into their roles, responsibilities and perspectives within the different work packages of the project.
A central aspect of the discussion was the opportunity for participants to better understand how the different components of the project are connected through the work of the individuals involved. This helped to make the structure of the project more tangible and accessible. Participants showed particular interest in understanding who is working on the project and how their work contributes to the overall objectives. This shift from abstract structures to individual contributions supported a stronger connection to the project.

What could be clearly observed during this session was that providing a behind-the-scenes perspective generated significant interest. Contrary to some assumptions that such insights might not be relevant for broader audiences, the session demonstrated that patients, citizens and also experts are indeed interested in understanding how projects like QUANTUM are structured, what challenges teams face and which considerations shape their work.

Based on the experience from Data Saves Lives Germany, patients and citizens are often perceived as lacking expertise or awareness when it comes to complex or technical topics. However, numerous interactions and engagements show a different picture.
What may not be known is often compensated by interest, openness and curiosity. This leads to a strong focus on what is meaningful, what has impact and what requires attention.

This does not happen by chance. Patients and Citizens are increasingly aware that they are part of an ongoing digital transformation in healthcare. There is a growing understanding that staying informed is not optional, but necessary.
In addition, many are aware of the limited resources within healthcare systems. As contributors through taxes and social contributions, there is a natural interest in understanding how health systems are organised, developed and improved for the future.

This interest is particularly strong among patients, whose primary concern is receiving good and reliable care. As a result, they actively follow developments that may influence how healthcare is structured and delivered.
The session highlighted that complex initiatives such as QUANTUM are not only defined by their technical outputs and deliverables, but also by the people who shape them. Making these individuals visible can contribute to building trust and strengthening engagement.

At the same time, the session reinforced the importance of humanizing complex topics. When participants are able to relate to the people behind a project, it can reduce perceived distance and support a more open and engaged dialogue.
Overall, the session provided a valuable closing element to the forum series, bringing together the different strands of discussion and reinforcing the importance of visibility, connection and trust in engaging patients and citizens.

3.3 Overall reflections of the Sessions from the Patients and Citizens Forum

Across the five Patients and Citizens Forum sessions, a consistent pattern emerged regarding how patients and citizens engage with complex topics such as health data, its secondary use and related policy developments.
The forum brought together participants from across Europe and beyond, reflecting a diverse mix of patients, citizens, representatives of patient organisations and experts from other projects and initiatives. This diversity provided valuable insights into how different groups perceive and engage with the topic of health data.

A key observation is that engagement does not start with technical concepts, but with understanding. Establishing a shared foundation and explaining core concepts in an accessible way is essential to enable meaningful participation.
Building on this, relevance plays a critical role. Participants engaged more actively when connections to their personal context and real-life implications were made clear. Without this, even well-developed concepts remained abstract and difficult to access.
Trust emerged as a central factor throughout the discussions. While regulatory frameworks such as the GDPR and the EHDS provide an important foundation, they are not sufficient on their own to create trust. Transparency, clear communication and the ability to understand how data is used in practice are essential elements in building confidence.

Closely linked to this is the role of language. Different stakeholder groups within the healthcare ecosystem often use their own specific terminology and ways of communicating. While this works

within individual groups, it can create barriers in cross-group interactions. Patients and citizens may struggle to understand experts, while at the same time experts may not always be aware of these communication gaps.
Throughout the forum, particular attention was therefore given to encouraging speakers to use clear and accessible language and to explain technical terms where necessary. This was found to support mutual understanding, reduce barriers and contribute to building trust.
At the same time, the sessions highlighted the importance of orientation. The challenge is often not a lack of information, but rather the difficulty of navigating complex and fragmented content. Structured, contextualized and accessible communication is therefore key to supporting understanding and engagement.

Another important insight relates to participation and perception. Patients and citizens are often perceived as lacking expertise in technical domains. However, the discussions and interactions within the forum indicate that this assumption does not fully reflect observed behaviour. Interest, curiosity and a willingness to engage were consistently present, particularly when individuals were given the opportunity to understand and contribute in a meaningful way.
This is also linked to a broader dynamic within the healthcare ecosystem. The need to overcome existing silos—frequently highlighted within patient advocacy—remains a critical factor. Creating spaces where different perspectives can meet and interact on equal footing is essential for fostering shared understanding and collaboration.
In addition to these qualitative observations, participation patterns across the sessions provide further context on how different topics were received.
The first session showed the highest level of participation, including a notable number of participants from expert backgrounds. This indicates a broad initial curiosity towards the topic of health data and its relevance across different stakeholder groups.

As the sessions progressed and topics became more specific and complex, participation numbers gradually decreased. This may reflect different dynamics. For expert audiences, some of the discussions may have been less aligned with their specific areas of focus, while for patients and citizens, the increasing complexity of the topics may have required more time and cognitive engagement.
At the same time, the final session demonstrated a renewed increase in participation. The focus on providing a behind-the-scenes perspective on the project, including the people and structures involved, was well received by participants.

This observation indicates that, beyond technical or conceptual discussions, there is interest in understanding how projects are organised, who is involved and how decisions are shaped. Making these aspects visible can therefore contribute to sustaining engagement and strengthening the connection between projects and their audiences.

Finally, the importance of human connection became evident. Making visible who is behind a project, how work is organised and what motivates those involved can significantly reduce perceived distance and support engagement. Complex initiatives are not only defined by their outputs, but also by the people who shape them.
Taken together, these observations underline that meaningful patient and citizen engagement requires more than providing information. It requires a structured, transparent and inclusive approach that considers understanding, relevance, trust, language and connection as key elements for long-term engagement—particularly in the context of European initiatives such as the EHDS and the development of a Health Data Quality Label.

4 Outcomes and conclusions

4.1 Summary of results - Patients and Citizens Forum

Across five online sessions, the Patients and Citizens Forum created a dedicated space to engage patients and citizens with topics related to health data, its secondary use and broader developments such as the European Health Data Space (EHDS).
The sessions consistently included patient representation, ensuring that discussions were grounded in real-life perspectives and experiences.
The only exception was the final session, which intentionally focused on providing a behind-the-scenes perspective on the project and its contributors. Participants came from across Europe and beyond, representing a diverse mix of patients, citizens, patient organisation representatives and interested experts. The sessions demonstrated that interest in the topic extends across different age groups and educational backgrounds.

A key observation is that engagement with topics such as health data does not start with technical concepts, but with understanding. Establishing a shared foundation and explaining core concepts in an accessible way proved essential to enable meaningful participation.

Building on this, relevance emerged as a critical factor. Participants engaged more actively when connections to their personal context and real-life implications were made clear. Without this, even well-developed concepts remained abstract and difficult to access.

Trust was identified as a central element throughout the sessions. While frameworks such as the GDPR and the EHDS are known to many participants, there is often limited understanding of their practical implications. This gap between awareness and understanding can lead to uncertainty and reduced trust.
Closely linked to this is the role of language. Different stakeholder groups within the healthcare ecosystem often use their own terminology, which can create barriers in cross-group communication. Ensuring clear and accessible language, as well as explaining technical terms, proved essential to support mutual understanding and trust.

The sessions also highlighted the importance of orientation. Participants are often not lacking information, but rather face challenges in navigating complex and fragmented content. Structured and contextualized communication is therefore key to supporting engagement.
Another important observation relates to the need for more direct exchange formats, such as roundtables, where different stakeholder groups—particularly experts and patients—can meet and engage in dialogue.

The sessions demonstrated that perceptions of realities and priorities within the healthcare system can differ significantly. What is highly relevant from a project or expert perspective—such as the secondary use of health data—often has a lower priority for patients, who primarily focus on primary health data that directly supports their daily disease management, treatment decisions and interactions within the healthcare system. Patients are continuously navigating the healthcare system, making decisions related to their health, managing symptoms and dealing with the consequences of their conditions. As a result, their perspective is naturally centred around immediate and tangible benefits.
This highlights the need to provide sustained and long-term engagement opportunities that clearly communicate the relevance and impact of secondary health data use. While its benefits may not be

immediately visible, both experts and patient experts recognize its importance in improving therapies, supporting decision-making and increasing the efficiency of healthcare systems.
Bridging this gap between immediate patient needs and longer-term system benefits is essential—not only for broader understanding, but also for the successful implementation and impact of initiatives such as QUANTUM.
In addition, the forum demonstrated that patients and citizens are not passive recipients of information. While they may not always have technical expertise, they compensate with interest, curiosity and a strong focus on what is meaningful and relevant.

Finally, the importance of human connection became evident. Providing insights into the people behind the project and their work helped reduce perceived distance and strengthened engagement.
Taken together, the Patients and Citizens Forum shows that meaningful engagement requires more than providing information. It requires accessible communication, clear relevance, trust-building measures and the inclusion of diverse perspectives across Europe.

4.2 Conclusions – Patients and Citizens Forum

The experience of the Patients and Citizens Forum demonstrates the value of dedicated engagement formats that focus specifically on patients and citizens within complex European health data initiatives.
Across five sessions, it became evident that meaningful engagement requires more than providing information. Understanding, relevance, trust, orientation and connection were consistently identified as key elements to enable participation.
The forum showed that patients and citizens are willing to engage with complex topics such as the secondary use of health data when these are communicated in a clear, accessible and relevant way. Interest was observed across different ages, backgrounds and levels of expertise.
At the same time, the discussions highlighted that engagement is not a one-directional process. Differences in perspectives between stakeholders, particularly between experts and patients, require formats that enable dialogue and mutual understanding. Creating spaces for exchange—such as roundtables—can support bridging these differences and contribute to more balanced discussions.

The forum also underlined the importance of communication as a central element of engagement. Language, structure and context strongly influence whether information can be understood and applied. Without these elements, even well-developed concepts may remain abstract and difficult to access.
Another important aspect relates to the need for sustained and long-term engagement. While primary health data is immediately relevant for patients in their daily lives, the value of secondary data use is often less visible. Continuous communication and accessible explanations are therefore necessary to support awareness and understanding over time.
Finally, the forum demonstrated that human connection plays a key role in engagement. Making visible who is behind a project, how decisions are shaped and what motivates those involved can reduce perceived distance and support trust-building.

An important observation relates to the sustainability of engagement beyond the lifetime of individual projects. While projects such as QUANTUM may conclude or transition into follow-up initiatives, the communities engaged throughout these processes remain.
If the objective is to meaningfully involve patients, citizens and the broader public in topics such as health data use, continuity beyond project timelines becomes an important consideration. Initiatives of high relevance for the future use of health data benefit from remaining visible and accessible within patient communities, among informal carers and across society.

At the same time, the sessions demonstrated that there is clear interest and curiosity among patients and citizens. Supporting and further developing this interest through accessible knowledge and continued engagement opportunities can help to sustain this momentum.
This also represents an important support mechanism for patient organisations, which often operate with limited resources while addressing a wide range of responsibilities. Making knowledge and insights from projects such as QUANTUM accessible to these organisations can support their capacity to inform and engage their communities.
This is further reflected in discussions within patient communities. In one exchange within the context of Data Saves Lives Germany, a representative of a patient organisation expressed the challenge as follows:

“We are experiencing so many changes in disease management—how are we supposed to keep up with all of this?”

This highlights the current reality many patient organisations are facing. Often relying on voluntary work and limited resources, they are managing multiple tasks, including patient support, information provision and responding to ongoing system changes.
At the same moment, they are actively engaging with new developments, for example by providing information and training on topics such as the electronic patient record in different countries. These efforts, however, also illustrate the limits of what can be achieved without additional support.
If projects such as QUANTUM take these conditions into account and contribute to providing accessible knowledge and structured information, this can support patient organisations in their work and strengthen engagement within patient communities.
The online sessions created a clear entry point to raise interest and initiate engagement among patients and citizens. At the same time, the experience indicates that existing frameworks and communication approaches for engaging patients and citizens may require further development.

While the sessions were effective in initiating engagement, they also highlighted limitations in reaching and sustaining broader interaction within the given project setting.
Extensive efforts were made to create visibility for the project across different formats and settings, including conferences and events. However, the experience suggests that traditional dissemination approaches alone may not be sufficient.
Aligning communication channels with where patients and citizens are already active, and moving beyond one-directional communication towards more interactive and participatory formats, can contribute to a more sustainable presence.
Such an approach—combining knowledge-sharing, interaction and continuity—can support trust-building, strengthen understanding and contribute to long-term engagement with health data initiatives.

Annexes

- Slide Deck of the Dissemination Event with Results from 28.05.2026 Available here
- Citizen & Patient Visibility Scan

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Birgit Bauer, european digital health academy gGmbH

From Abstract to Understanding: We Talk About Health Data — But Do People Understand It?

About Birgit Bauer

- Founder, european digital health academy gGmbH - edha (Non Profit)
- Founder, Data Saves Lives Germany (DSL DE)
- International Advisor on patient-centred health data and digital health
- Member, OECD DFFT Expert Community
- Contributing to a policy brief on public interest in secondary use of health data & EHDS
- Member of the Ad-Board of the DigiHealthDay-S / efpia PTT
- Speaker, Expert, Networker
- Journalist, Social Media Expert
- Patient expert, informed by lived experience

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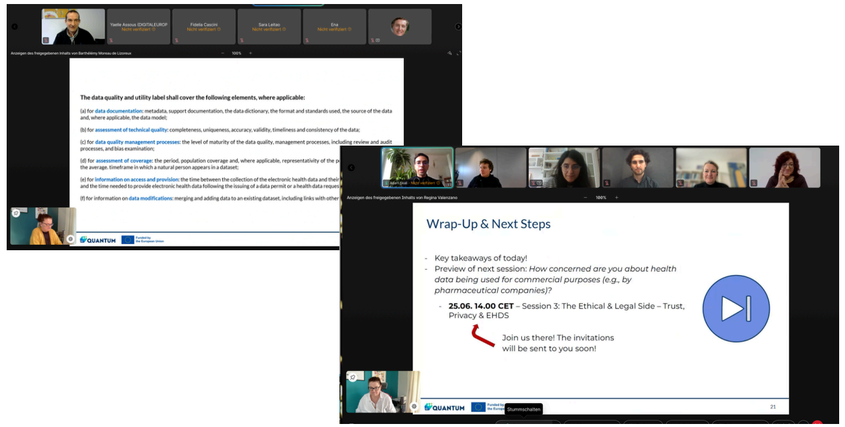
DATA SAVES LIVES
DE

I was asked to bring in the patient and citizen perspective.
And what we found is actually quite simple — but also quite uncomfortable.”

Patient and Citizen engagement in QUANTUM

To understand how patients and citizens perceive health data, we did the following:

- 5 patient & citizen sessions (WP5.5)
- Outreach via EDHA & DSL DE networks + the Team / Network
- Ongoing listening, Discussions, Social Media Screening, (Q3 & Q4/2025):
- → conversations with patients & citizens
- → How is the understanding of secondary use of health data?



Patient and Citizen engagement in QUANTUM

The 5 patient & citizen sessions (WP5.5)

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What Kind of Health Data Do We Have?

Understanding Health Data Types and Their Impact

25 March | 14.00 CET
Birgit Bauer - edha - european digital health academy gGmbH
Fidelia Fascini - Università Cattolica del Sacro Cuore
Beatriz Barros - Sciensano

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Trust, Privacy & the EHDS

The Ethical & Legal Side of Health Data

25 June | 14.00 CET

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QUANTUM - Meet the Faces behind the Project

April 14th, 2026

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Why should I care?

The Benefits of Health Data Labeling for Patients & Citizens

6 May | 14.00 CET

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The European Health Data Space

Progress, News, and What's Next For Patients

8 October | 14.00 CET

What People actually see - From our analysis in Q3 & 4 2025

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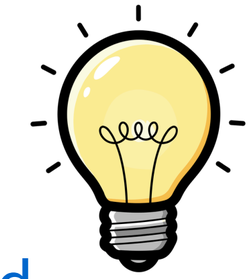
The visibility scan shows what an ordinary person actually sees when searching тor QUANTUM or health data labelling / health data quality label .

- Desk-based visibility scan (search engines & public sources)
- Focus on accessibility, clarity and citizen relevance

Key findings:

- QUANTUM is mainly visible through institutional sources
- Search engines react on “Health Quality Label” but not on “Health Data Quality Label” - there are some less explanations but “Health Data Quality Label” was misunderstood (AI annotation instead of quality/trust)
- **No plain-language explanation for citizens -** changed in Q1/ 26 Comms brought a Flyer and a Video to explain QUANTUM

What we observed - Limited visibility for patients and citizens



- Communication mainly reaches experts and institutions - via LI, bluesky and website
- Patient organisations: moderate, mostly reactive, interested but very often overwhelmed with “additional themes”
- Citizens and patients: very low visibility - more interestes in primary health data
- Health data topics remain abstract and disconnected - not well explained in most of the countries (EU Member States)
- No relatable entry point for non-experts

These observations highlight how differently the project is perceived depending on the audience.

Core Learning - Participation does not automatically lead to understanding

- Health data quality labelling happens behind the scenes - abstract and hidden for most of the people
- It is invisible in everyday life - seems that there is no value in it especially for patients
- Without context, people cannot engage - and don’t trust

Based on these observations, one central learning emerges:

Understanding must come before engagement -

Explain > Understanding > Trust and Engagement!

What Patients actually say - From a Patient Perspective!

When speaking directly with patients, a very clear perspective emerges:

“They can have my data – as long as I benefit from it. How they sort it is not my concern.”

Quote from a Person living with a chronic disease for more than 12 years

What Patients are really looking for:

- Focus on care, outcomes and benefit - Information about the Disease, Therapy Options, Digital Tools for the Disease Management, Clinical Trials
- Not on technical processes
  Transparency and relevance matter most - Privacy and Data Protection is key

The Gap between systems and real-world use

- Strong focus on infrastructure and tools in Projects
- Limited focus on understanding and visibility for Patients and Citizens
- Processes are invisible → no real engagement possible
- Low interest is not lack of willingness

→ it is lack of relevance and context

Context:

Similar challenges highlighted by OECD,
Confirmed by recent research

Communication & Engagement: Communication needs to meet people where they are

Communication plays a central role in closing this gap between systems and real-world use.

- Visibility depends on being present where patients are
- **Channel choice should follow relevance, not convenience**
- Communication is currently mostly one-way - it is a dialogue
- Interaction is needed to build trust and visibility - relationship with stakeholders creates connections - creates new networks - helps to community / capacity building

Or:

- **Explaining what we do builds understanding and trust > Trust enables participation**

Sustainability & EHDS - Projects end - but the need for understanding does not

Looking ahead, this becomes even more important in the context of the European Health Data Space.

- Health data initiatives (e.g. EHDS) are gaining momentum and help to create a better “healthy future” for Citizens.

- Public understanding becomes critical for uptake
- Communities should not be built and then left behind
- They require continuity, trust and ongoing dialogue

Sustainability & EHDS - Projects end! The need for understanding does not.

From insight to action - And this is exactly where our work continues

Health begins with understanding

edha accompanies you in the digital health world - comprehensibly and at eye level.

- No pressure.
- No technical jargon.
- But knowledge that grows - like you.

"Where others see the crack, we grow into it."
edha - a grassroots initiative for digital health literacy."

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https://edha.academy

Contact: info@edha.academy or DSL.DE@edha.academy

https://www.datasaveslives.de

This is why initiatives like Data Saves Lives Germany focus on building the missing layer — understanding, context and trust.

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Thank you!

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References:

- OECD (2024/2025). Public engagement and trust in the secondary use of health data - https://www.oecd.org/content/dam/oecd/en/publications/reports/2025/06/facilitating-the-secondary-use-of-health-data-for-public-interest-purposes-across-borders_0432b99b/d7b90d15-en.pdf
- OECD DFFT Expert Community insights and ongoing policy work
- European Commission / EHDS context - Need for citizen trust, transparency and understanding for uptake of secondary use of health data

Citizen & Patient Visibility Scan – WP5.5 Communication Update

Reality check on QUANTUM's public presence and citizen relevance

Prepared by European Digital Health Academy gGmbH (EDHA)
WP5.5 – Communication, November 2025

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Why this scan was initiated

- WP5.5 aims to support citizen and patient engagement within QUANTUM.
- Despite ongoing communication activities, Online Sessions, just little is known about the project’s visibility beyond professional audiences.
- This scan provides a quick assessment of what citizens and patients can actually find when they search for “Health Data Label” or “QUANTUM project”.
- The findings indicate a significant gap between intended outreach and public perception.

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How the scan was conducted

- Conducted in October / November 2025 by EDHA within WP5.5’s citizen communication remit.
- Used public search engines (Google, Bing, DuckDuckGo) + EU health data portals.
- Search terms: “QUANTUM project”, “Health Data Label”, “health data quality label”.
- Focus: accessibility, clarity, citizen language, public relevance
- Outcome: snapshot of what an ordinary person sees online.

This was a desk-based visibility scan — not an academic study, but an evidence-based communication review.

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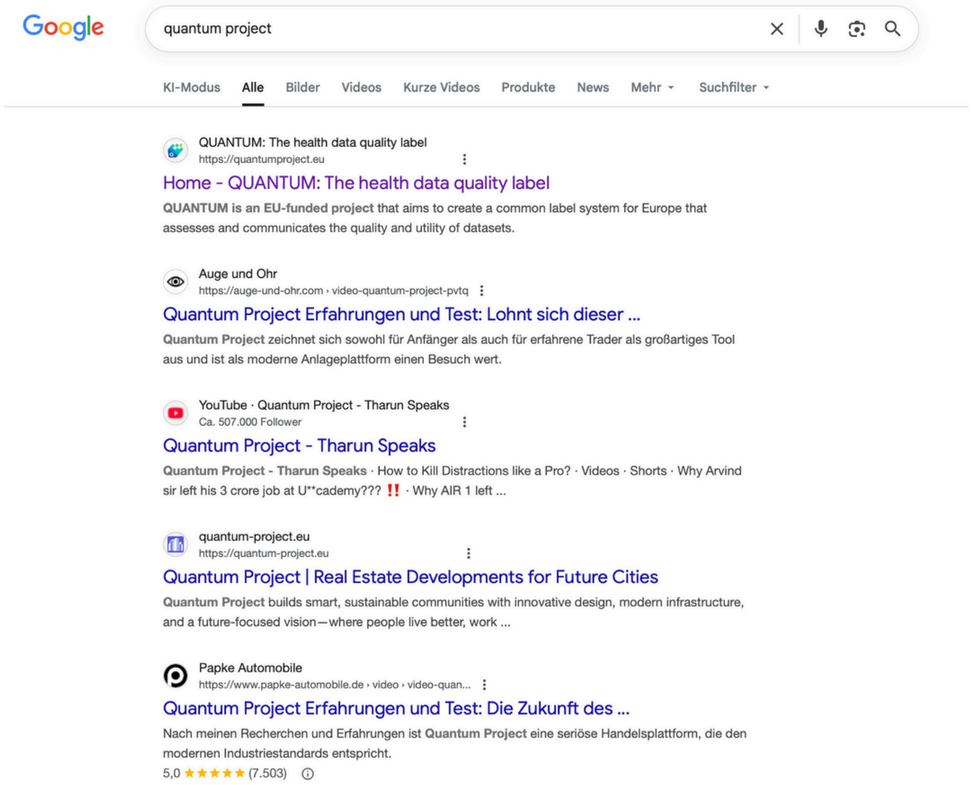
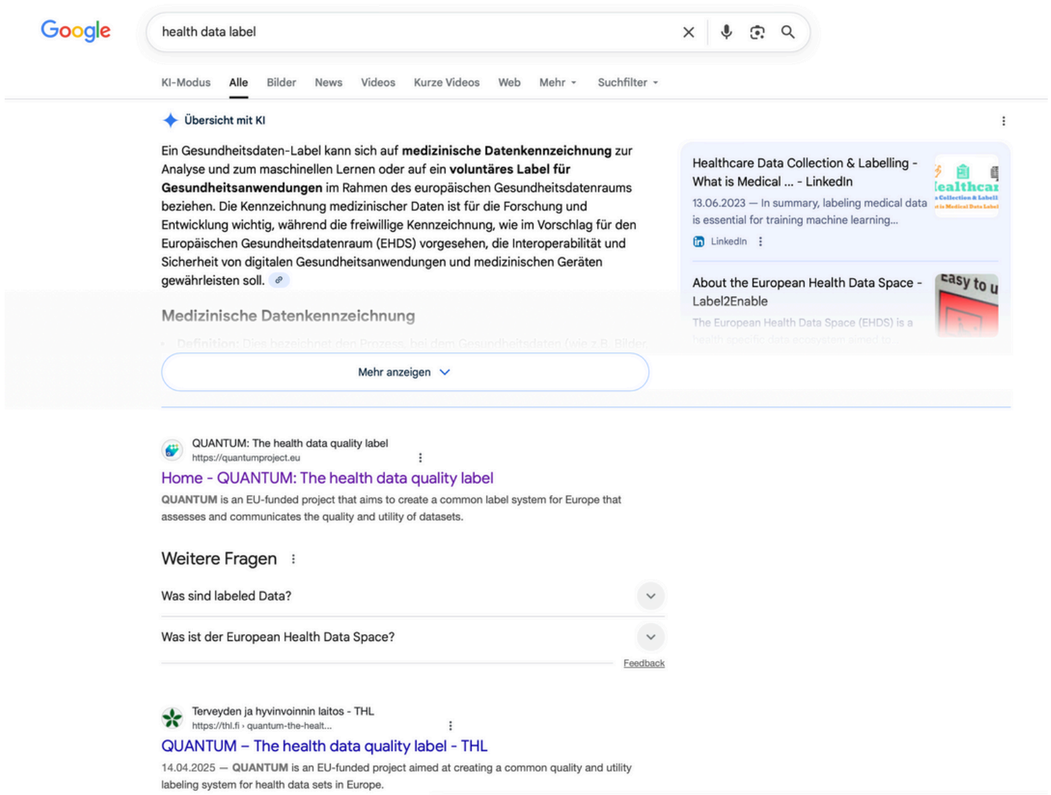
How the scan was conducted



Pic 1: Quantum is identied from Pos. 2 as AI, Estate Development and Trading, there is no patient relevant Information visible



Pic.2 AI is explaining the Term, offers more info, then QUANTUM comes around, other insitutions / associations reporting about the project but also here: No patient relevant Links / Info just technical info.

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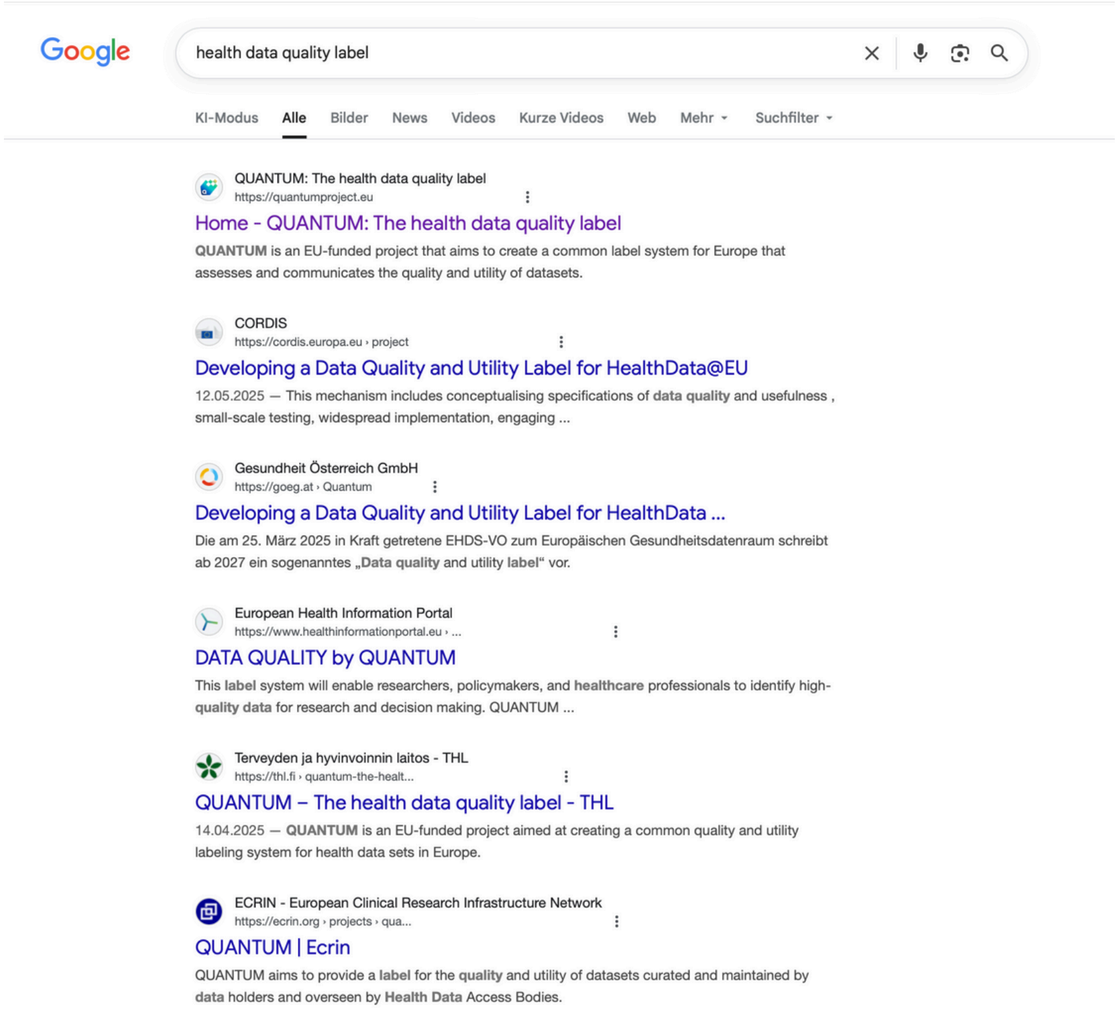
How the scan was conducted



QUANTUM is on Pos 1 but then again no relevant or user friendly information. Just technical info.

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Current public visibility

Findings:

QUANTUM appears mainly via institutional sources:

quantumproject.eu

Digital Europe press release

Health Information Portal

No plain-language explanation of the project, its goals, or its benefit for citizens.

“Health Data Label” is widely interpreted as AI data annotation, not data quality or trust.

The QUANTUM Tool is visible only through technical documentation – not explained for non-experts.

From a patient's / citizen’s point of view, QUANTUM currently does not exist in any relatable or understandable way, the term “Health Data Labeling” doesn’t exist in the patient communities and isn't mentioned in regards of Patient Organizations or Patient Communities.

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Who QUANTUM currently reaches

Audience	**Visibility**	**Language**	**Engagement** Type
Researchers / Policymakers	High	Technical	Active
Patient organisations	Moderate	Institutional	Reactive
Citizens / Patients	Very low	Absent	None

Observation:

Even the project's main output — the QUANTUM Tool — is presented in technical language, visible only to insiders.

If it is not designed for citizens, the team should clarify again what "citizen engagement" means in this context.

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Patient & Citizen Insights – Reality Check

When it comes to data, people care about care – not labels.

Summary of conversations with patients and citizens:

- Health-data labelling is an internal process that happens after care and out of view.
- Because it’s invisible, citizens cannot be expected to engage with it.
- Interest appears only when they actively share data (for research or treatment).

What they really want to know:

- What data of mine are used?
- For what purpose, where and when?
- What was achieved with it?
- They value transparency, understandability and visible benefit.
- Terms like primary and secondary use are irrelevant in daily life.
- Healthy citizens rarely think about data until illness creates personal relevance.

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Patient & Citizen Insights – Reality Check

They should make sure I get the care I need.
They can have my data – as long as I also benefit from the research that uses it.
How they sort it is not my concern.” – Patient, Germany

Patients want good care and results, not data labels.

Communication should start with relevance, not process.

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From intention to reality

- The scan shows that QUANTUM’s external communication currently serves more experts, not patients & citizens.
- This is not why we don’t work on it - the reason is: This is not due to missing effort – health data labelling simply happens behind the scenes.
- We can see this also regarding the EHDS - at the moment interest is at the bigger Patient Organizations, but not in Patient Groups, Citizens are not interested in general. They are healthy. :-)
- The low numbers of Health Literacy are one factor - HLS GER 03 is one example from Germany showing clearly: People are not always able to find, understand and use health information to make decisions for their health. It is similar for Digital - and Data Literacy.
- This explains why citizen interest is low – not due to ignorance, but because the process is invisible and disconnected from personal health experience.
- To build real trust, the project must close the visibility gap.
- EDHA is ready to provide content and strategy for this shift.

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Making QUANTUM visible and relatable - QUANTUM

- We recommend: Go with the Patients - this is the best option
- Create a QUANTUM Glossary – a living, plain-language resource explaining key terms - the best option to grow Digital - Data and Health Literacy and use those #digitalliteracy #dataliteracy and #healthliteracy #patientempowerment
- Inspired by DSL DE's Fachgedöns model for citizen-friendly health data communication - this was already shared with the team of WP 5 and also shared with the Belgium Health Data Authority by Barthélémy some weeks ago - at the moment we don't have any connections as this was not shared, so he can give more info about this.
- Add a For Patients / Citizens section on the QUANTUM website with FAQs and visuals, bring in regular BlogPosts coming from WP Members - 2 / month = better content and more keywords for Search Engines (SEO influence) .
- Have a look with us on the Social Media Analytics to find more insights - we can help here.
- Current communication functions mainly as a one-way monologue; interaction within real patient communities would significantly improve visibility and algorithmic reach.

This is not about extra work –
it's about making existing work visible to the people whose trust we aim to earn.

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What we can to with edha and DSL DE

- **EDHA and DSL DE offer established access to citizen and patient communities that can support QUANTUM's outreach without creating additional workload.**
- **DSL DE had decided to integrate the "Health Data Labeling" Term to our Fachgedöns - this is under production and we will bring out the Online Version during the next days and present it on our Website and the Channels.**
- **We also plan a Session to present the Fachgedöns to our community. One Session will be in German one will be in English. We offer QUANTUM to come to both sessions in our discussion panel and express the importance of knowing technical terms to give insights to the community. Health Data Labeling can be mentioned as example. This is planed by the end of January, depends on availabilities and progress. We welcome a representative to the sessions but we also need a german speaking person for the German community.**
- **We publish the DSL DE Magazine 2026 by beginning of April 2026 - the magazine is already in progress but we also plan a campaign with blogposts with actual Experts / Themes and we can give the opportunity to QUANTUM to contribute a Blog Post. DSL DE Kompass will be in German and English Language**
- **At the moment we are working on the edha platform and can offer the team to create a extra lesson about health data labeling - edha is from patients for patients, we open our website during the next days and work on the moodle platform behind the scenes - we can offer a space here too.**

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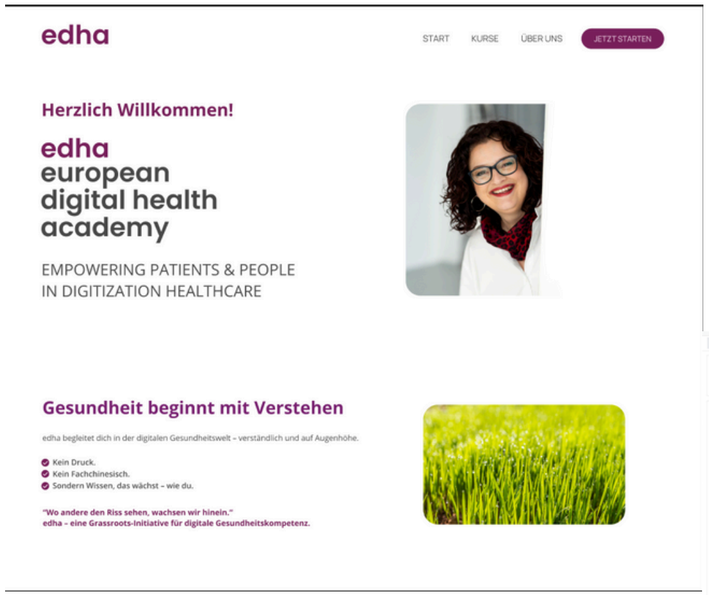
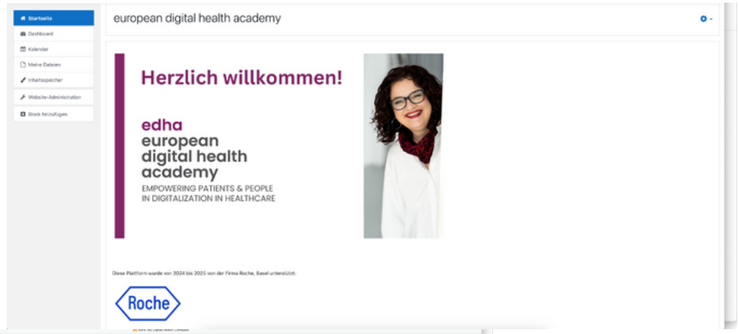
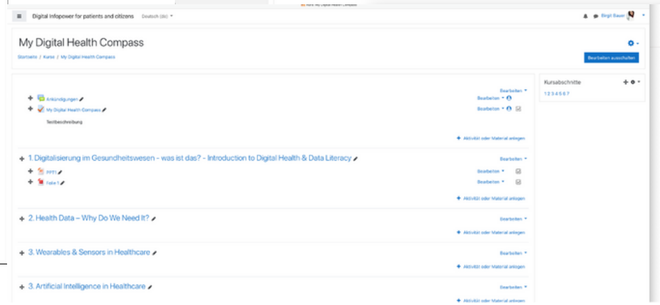
Some screenshots







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